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# **Psychological Distress and Positive Gain in Mothers of Children with Autism, With or Without Other Children with Neurodevelopmental Disorders**

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## **Abstract**

Although a wealth of literature has focused on the parenting experiences of mothers of children with autism spectrum disorder (ASD), there is a lack of research about mothers who are parenting a child with ASD, and who have other children with neurodevelopmental disorders. In this matched-comparison study, 10 mothers of a child with ASD and other typically developing children (ASD-TD) were compared to 10 mothers of a child with ASD who also had other children with neurodevelopmental disorders (ASD-NDD). Mothers completed self-report measures of mental health and positive gain. Results indicated no significant between-group differences for mental health, although mothers in the ASD-NDD group reported increased positive gain compared to mothers in the ASD-TD group. Further research is needed to understand practical support needs and theory development

**Key words:** autism, neurodevelopmental disorders, siblings, psychological well-being, mental health, neurodiversity

## **Introduction**

Mothers of children with autism spectrum disorder (ASD) show similar positive affect and feelings of capability as do many other mothers (Totsika *et al.*, 2011). However, a wealth of research demonstrates that mothers of children with ASD experience profoundly impacted mental health, including stress, depression, and anxiety compared to mothers of typically developing children, and to mothers of children with other neurodevelopmental disorders (NDDs; Adams *et al.*, 2018; Abbeduto *et al.*, 2004; Lee *et al.*, 2008, Olsson & Hwang, 2001; Ingersoll & Hambrick, 2011). Mothers of children with ASD and also mothers of children with other NDDs are at greater risk for psychological difficulties for a number of reasons, including

increased levels of child behaviour problems, reduced financial and social supports, and poorer child sleep (Benson, 2010; Zeedyk *et al.*, 2014; Garner *et al.*, 2011; Hodge *et al.*, 2012; Robinson-Shelton & Malow, 2016).

Psychological well-being for mothers of children with ASD has been studied extensively, but often without explicit recognition of a family systems perspective (Cridland *et al.*, 2014, Hastings, 2016). This perspective recognises that all family members have an influence on, and are influenced by, one another (Cox & Paley, 1997). Where such a framework has been applied, it has tended to explore parental relationships, or how outcomes for mothers relate to their child with ASD and typically developing siblings (e.g. Hastings *et al.*, 2005; Hastings *et al.*, 2014) as opposed to the impact of raising *multiple* children with NDDs.

A limited number of studies have considered maternal well-being when raising multiple children with NDDs. Ha *et al.*, (2008) found that parents who had more than one child with NDDs (diagnoses including attention deficit/hyperactivity disorder (ADHD) and learning disabilities) showed associated, increased negative affect and elevated somatic symptoms. In qualitative research, Kimura & Yamazaki (2013) explored mothers' experiences of parenting multiple children with NDDs, including ASD, ADHD, and developmental delay. Using interpretative phenomenological analysis, a super-ordinate theme described "accumulating physical and mental fatigue", illustrating mothers' reports of being unable to rest due to childcare demands, and feeling unsupported (Kimura & Yamazaki, 2013, p. 1312).

While these studies offer an important perspective on the parenting experience of mothers of multiple children with NDDs, the range of different NDDs included makes it difficult to disentangle the influence of specific diagnoses, such as ASD. This was considered, however, in a matched-comparison design by Orsmond *et al.* (2007), here mothers of one child with ASD and a second typically developing child, were compared with mothers who had a child with

ASD and an additional child with a disability (including ASD, ADHD, learning disability, or psychiatric disorder). The mothers of multiple children with diagnoses reported elevated anxiety and depression, and lower levels of family adaptability and cohesion, compared to the mothers of one child with ASD and a typically developing child. Therefore, previous literature appears to suggest that parenting a child with ASD alongside children with NDDs may lead to additional negative effects on maternal well-being. Similarly, as Dovgan & Mazurek (2018) indicate, differential effects on families can be seen as related to differing children's diagnoses. Parents of children with ASD or intellectual disabilities, for example, experience more financial burdens and respite needs than parents of children with ADHD, yet parents of children with ADHD demonstrated greater counselling needs compared to parents of children with intellectual disabilities. As such, families where children receive multiple, differential diagnoses may experience an increased number of "family burdens" and a knock-on effect for their parental well-being (Doygan & Mazurek, 2018, p. 872).

Given the limited existing research examining the family experiences of raising multiple children with NDDs, additional studies are needed to inform support for these families. Little is known, for example, about the experience of mothers raising more than two young children with NDDs. Orsmond et al. (2007), for example, included children with a mean age of 21.54 years (ranging between 10 and 52 years). In addition, as NDDs often co-occur across siblings, it is important to understand neurodiverse families' needs and perspectives (Farone et al., 1996; Ozonoff et al., 2011; Jokiranta -Olkonien et al., 2016). Existing research has also not explicitly investigated positive maternal outcome measures and, therefore, little is known about any potential positive consequences of raising multiple children with NDDs. One such construct in NDD research is positive gain (Adams et al., 2018; Griffith et al., 2011): positive parental perceptions of the impact of raising a child with a disability.

The aim of the current study was to compare the well-being of mothers with one child with ASD and other typically developing children (ASD-TD), with that of mothers of a child with ASD who have other children with NDDs, including children with multiple diagnoses (ASD-NDD). Well-being was operationalised as both mental health (anxiety, depression, and overall psychological distress) and positive gain. Based on the previous literature, mothers in the ASD-NDD group were expected to have significantly increased negative mental health outcomes compared to mothers in the ASD-TD group. As no previous studies have considered positive gain in relation to both mothers with one child with ASD and otherwise TD children, and mothers with a child with ASD and other children with NDDs, no predictions were made for this outcome.

## **Method**

### ***Participants***

Twenty mothers of children with ASD participated in this study, divided into two matched groups (see Procedure): ASD-NDD (N=10) and ASD-TD (N=10). Maternal and child characteristics for these families are provided in Table 1. Diagnoses for ASD and other diagnoses were obtained via parent-report.

ASD-NDD families had an average of three children (four families with two children, two families with three children, and four families with four children). Mothers provided demographic data and diagnoses for 30 children overall, 10 of whom were considered the ‘target child’ with ASD for matching purposes. Most of these target children had an additional diagnosis as well as ASD (80%) and these multiple, co-occurring conditions ranged from one to six (mean=3.63 conditions).

A further ten mothers had one child with an ASD diagnosis, and their other children were typically developing (ASD-TD; Table 1). This group also had an average of three children per

family (four families with two children, two families with three children, and four families with four children). Again demographic and diagnostic information as provided for a total of 30 children, with 10 children with ASD considered to be the target child for matching purposes.

[INSERT TABLE 1]

## ***Measures***

### *Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)*

The HADS is a reliable and widely used measure to assess anxiety and depression within community samples (Breeman *et al.*, 2015). The 14 items (7 for depression e.g. ‘I feel as if I am slowed down’, and 7 for anxiety e.g. ‘I feel tense or “wound up”’) are rated on a four point scale (0 to 3) and yield independent scores for anxiety, depression, and a combined overall psychological distress score. Higher scores indicate increased symptoms or distress. The clinical cut-off score for both anxiety and depression is recommended as scores of 10 or above (Crawford *et al.*, 2001). Previous research with mothers of children with ASD indicates a good internal consistency for anxiety (.87) and depression scores (.82; Hastings, 2003).

### *Positive Gain Scale (Pit-ten Cate, 2003)*

This measure was developed to assess positive aspects of parenting children with disabilities. It includes seven items rated on a five-point scale of agreement, including ‘since having this child I feel I have grown as a person’ and ‘since having this child my family has become closer to one another’. Lower scores indicate increased positive gains reported by mothers. Previous literature indicates good internal consistency for this scale (.86) when used with mothers of children with ASD (Jones *et al.*, 2014). Although mothers in the ASD-NDD group completed positive gain scores for each child, only the scores for their ‘target’ child are included in this study. The ASD-TD group completed a positive gain score in relation to their child with ASD.

## ***Procedure***

This study was approved by the research ethics committee at the first author's institution prior to the commencement of the study. The mothers in the ASD-NDD families were recruited via social media or schools. After being provided with an information sheet, informed consent was obtained in writing from all mothers included in the study. Mothers who wished to participate were sent a questionnaire pack, including the aforementioned measures. A pre-paid envelope was also provided for questionnaire return. The inclusion criteria were two or more children with at least one differing NDD. Fourteen mothers completed questionnaires, of whom ten were included in this study with a focus on ASD.

These ten mothers were then selectively matched to mothers in the ASD-TD group, who had only one child with ASD, with otherwise typically developing children. These mothers were from a previous family research study (Petalas *et al.*, 2012). Although both mothers and fathers were invited to participate in this research, only mothers meeting inclusion criteria for the ASD-NDD group responded, and thus could only be matched with mothers from the Petalas *et al.* (2012) sample. Families were selected from the Petalas *et al.* (2012) sample if they matched the ASD-NDD group on various maternal and target child characteristics. For maternal characteristics, matching criteria were: total number of children, marital status [married/living with partner vs. single], employment status [in paid employment vs. not in paid employment], and educational level [below undergraduate degree level vs. undergraduate degree level or above]. Regarding the target child with ASD, if multiple children had an ASD diagnosis in the ASD-NDD families, a child was selected for matching purposes using a random number generator. Families were then matched across the samples on the age of their target child with ASD (acceptable threshold of +/- 2 years) and this child's gender.



Overall, matching was successful, with 80% of participants matching on all criteria. However, two discrepancies occurred. One mother in the ASD-NDD group had missing data for educational level (and so matching status was unknown), and one match did not conform to the employment criterion.

## **Results**

Paired samples t-tests were used to compare the matched groups of mothers on anxiety, depression, overall psychological distress, and perceptions of positive gain. The results of these analyses are shown in Table 2. No statistically significant group differences emerged for anxiety, depression, or overall psychological distress. Due to the small samples, proportions of mothers meeting the clinical cut-off for anxiety and depression in each group was explored descriptively (see Table 2). In the ASD-NDD group, 50% (N=5) of mothers reached the clinical anxiety cut-off, compared to 80% (N=8) of mothers in the ASD-TD group. For depression, 30% (N=3) of mothers in the ASD-NDD group reached the clinical cut off, compared to 40% (N=4) of mothers in the ASD-TD group.

Mothers in the ASD-NDD group reported significantly higher levels of positive gain compared to mothers in the ASD-TD group. The effect size for this difference was also large (see Table 2).

[INSERT TABLE 2]

## Discussion

The present study builds upon previous research by exploring the well-being of mothers raising multiple children with ASD and other NDDs. We did not find the expected between-group differences for mental health outcomes: anxiety, depression, and overall psychological distress. However, descriptively, the proportion of mothers reaching clinical levels of anxiety and depression was higher in the ASD-TD group than in the ASD-NDD group. These findings contrast with Orsmond *et al.*'s (2007) findings, where mothers of multiple children with disorders showed elevated anxiety and depression levels, compared to mothers of one child with ASD. The current findings require replication, but this discrepancy may be due to the small sample size in this present study (despite close matching of families), and may also be due to the different demographics (especially of age) of children between the two studies. Garner *et al.* (2011) for example, found that older children were more likely to have fewer positive interactions with their parents, which might contribute to impacted parental well-being. If replicated, and indeed explored in future qualitative research, one potential reason for reduced psychological wellbeing for mothers in the ASD-TD group may be that they are in a position to compare emerging behaviours and milestones between their child with ASD and their TD children. In ASD-NDD families however, as multiple children present with at least two sets of differing developmental trajectories and profiles, mothers may be less likely to perceive, or to be negatively impacted by, developmental differences.

Mothers in the ASD-NDD group perceived higher levels of positive gain compared to mothers in the ASD-TD group. This finding requires replication and exploration in more detailed research. It may, for example, be related to previous research suggesting that mothers with multiple children with NDDs strongly identify with the role of being a mother to children with various NDDs, and as a result perceive positive life change and a heightened sense of purpose (Kimura & Yamazaki, 2013). This difference may also be related to mothers of children with

multiple disorders feeling increased personal benefit of raising their children due to even the smallest of their children's achievements.

It is important to highlight the limitations of this research. Although this research indicates a potential area of interest for future study, no strong conclusions can be drawn given the small sample sizes. Mothers who responded to the social media advertisement for this study also might represent a sampling bias. Similarly, it is important to highlight the limitation that all children's diagnoses were only provided by parents, and not verified by the research team. No measures were taken of children's adaptive functioning or other characteristics, and this may limit the generalisability of these findings. Also, this research did not consider the impact of broader autism phenotype (BAP) on parental well-being, whereby parents could have their well-being directly affected as a result of themselves having sub-clinical autistic traits (e.g. due to an increased risk of depression due to shared genetic factors) or indirectly (e.g. due to parent behaviours such as rigidity which could lead to negative outcomes; Ingersoll & Hambrick, 2011). It is also important to note that the relatively privileged status of participants in this sample within the UK culture does account for the group differences in this particular study (due to the homogeneity of the sample). However, previous research supports the notion that the results should be replicated with more marginalised families (for example, those from ethnic minority groups). This is an important consideration due to the potential impact of culture on families' experiences of services and positive experiences (Blacher & MacIntyre, 2006; Carr & Lord, 2013).

Due to the small-scale nature of this research, it was necessary to identify families broadly as 'neurodiverse families'. Future research with larger samples would allow for greater exploration of the role of diagnosis of particular NDDs, but also exploration of important variables (e.g. child behaviour) across diagnostic boundaries. Similarly, in addition to matched-group designs, it is crucial to more broadly consider and qualitatively explore the experiences

of neurodiverse families (Kimura & Yamazaki, 2013). As well as contributing in-depth information about mothers' experiences, findings from such qualitative research could be used to provide insight into potential mechanisms that underlie group differences observed, which could then be fed back into matched-design studies as theoretically driven factors for matching (Stuart, 2010, Downey & Coyne, 1990). In terms of clinical recommendations, the positive gain results in this small scale study suggest the importance of not simply assuming that raising multiple children with NDDs must mean parents are burdened or experience greater struggle. Instead, these findings highlight the need to understand and explore the particular experiences and situations of each neurodiverse family with which a practitioner may work. More broadly, increasing our understanding of experiences and outcomes for neurodiverse families will not only allow for the development of both practical support and resources, but will also allow for the development of evidentially-grounded neurodiverse family systems theories.

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Table 1. Maternal and child characteristics		
Demographics	ASD-NDD	ASD-TD
<b>Maternal Characteristics</b>		
N	10	10
Married/Living with Partner	90%	90%
Paid Employment	50%	60%
Below Undergraduate Education	88% <sup>a</sup>	80%
White-British	90%	100%
<b>Child Characteristics</b>		
N	30	30
Age (mean)	10.1 (3.15)	11.02 (2.70) <sup>b</sup>
Male	87%	67%
ASD	12 (6 Target)	8 (8 Target)
Attention-deficit/hyperactivity disorder	10	-
Asperger's syndrome	6 (4 Target)	2 (2 Target)
Typically developing	6	20
Sensory processing difficulties	5	-
Moderate intellectual disability	3	-
IQ 21.1 micro duplication syndrome	2	-
Dyspraxia	2	-
Attention deficit disorder	2	-
Hypermobility	2	-
Global developmental delay	1	-
Pathological demand avoidance	1	-
Dyslexia	1	-
Dyscalculia	1	-
Developmental coordination disorder	1	-
Dysgraphia	1	-
Mixed anxiety and depressive disorder	1	-
Anxiety	1	-
Williams syndrome	1	-
Comorbidities (N of children with a comorbid diagnosis)	17 (8 Target)	0
<sup>a</sup> one mother did not report education status, data provided for 9/10 mothers		
<sup>b</sup> ages only available for 20/30 children (target child and closest aged sibling)		

\*p<.05

Table 2. Maternal well-being in families of children with ASD with or without other children with neurodevelopmental disorders

	ASD-NDD			ASD-TD					
	Mean	S.D.	Clinical Cases	Mean	S.D.	Clinical Cases	<i>t</i>	<i>p</i>	<i>d</i>
Anxiety	10.50	4.88	5	12.10	4.28	8	.747	.474	.24
Depression	7.30	4.07	3	7.70	4.16	4	.185	.858	.06
Psychological Distress	17.80	7.83	-	19.80	8.07	-	.486	.639	.15
Positive Gain	9.70	4.50	-	13.40	4.03	-	2.399	.040*	.76